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ABSTRACT

This booklet is designed to assist those who are responsible for coordinating and monitoring from a distance the care of an aging relative. It provides help in identifying problem areas and possible resources for support. It also provides information about creating a network of assistance that includes family, friends, neighbors, and social service workers, and contains suggestions for planning to make visits most effective. Suggestions are provided on making the most of limited visits, focusing on talking with the relative and observing how the person is living. A care management worksheet is provided which includes 16 statements about the elderly person's needs and well-being with suggestions for services needed, relevant readings, and available resources. Four additional statements deal with the perceptions of the caregiving relative, focusing on his or her stresses. A bibliography listing the resources suggested in the care management worksheet plus a list of free American Association of Retired Persons (AARP) resources are included; and seven books for sale to AARP members at discount prices are also listed. Suggestions on how to identify the older relative's informal support system and how to expand the existing support network are made. Methods for locating and using formal services are discussed and state units on aging are listed. It is suggested that the caregiver may wish to locate a Silver Pages Directory or consider a private geriatric case manager. Suggestions are also made on accepting formal services and dealing with the social service network. The booklet concludes with recommendations for the caregiver's own well-being. (ABL)

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MILES AWAY AND STILL CARING



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Introduction: Long-Distance Caregiving

*“**W**hen Mother first became ill, I took a leave of absence from work, thinking that in a few weeks she'd be back to normal. That was two and a half years ago. She's been going steadily downhill since. It hurts me so much to leave her in South Carolina, but I have to work and she refuses to move to Washington. My phone bills are extremely high and I'm beginning to have problems with my blood pressure—the doctor says it's nerves.”*



This woman lives several hundred miles from her ailing parent. She is feeling helpless and guilty because she does not know how to check on her mother's well-being. She, like many other Americans, is faced with “long-distance caregiving.”

Today, our society is a mobile one. Young and middle-aged adults frequently relocate for employment purposes. Older persons are also moving more often. In fact, during the 1970s, the number of retirement-age persons who migrated from state to state increased 58 percent.

People with ailing relatives living at a distance have many difficult questions and issues to address. Although most people realize that they cannot afford to travel back and forth to provide care, they may still experience a tremendous amount of guilt over not being physically present to help. They are frequently unfamiliar with the services available in their relative's area and consequently feel overwhelmed by the thought of having to identify community resources.

This booklet is designed to assist those who are responsible for coordinating and monitoring from a distance the care of an aging relative. It will help you identify problem areas and possible resources for support. It also provides information about creating a network of assistance that includes family, friends, neighbors and social service workers, and contains suggestions for planning your visits to make them most effective.

No matter how far away your aging loved one is, you can use this guide to help stay involved in maintaining necessary care.

Making the Most of Limited Visits



Commuting back and forth between cities or states is strenuous for anyone—even those not involved with caregiving. Those who *are* responsible for a relative may also experience financial strain, job stress and feelings of guilt and anxiety.

It's important that when you visit an older relative, you make the most of your time together.

Talk with your relative so that the two of you can analyze the situation, recognize problems, activate informal support networks and coordinate social services. Allow yourself enough time to accomplish necessary tasks, such as visiting social service agencies.

Be careful not to antagonize your relative, but rather enlist his or her involvement. You need to talk honestly about your relative's ability to remain in the current situation and the supports that are needed. You and your relative's perception of the situation may differ greatly. You may think that he or she is unable to perform certain tasks when all that's needed is more time to complete the task. Remember that a person may be willing to sacrifice a great deal to remain in his or her own home. As long as there is no threat to their physical or mental well-being, older persons should maintain control over their own lives.

If your relative is still able to remain independent, you might want to establish a back-up plan of support in case needs change in the near future.

While you're visiting, be observant. Do you notice anything unusual? Is your relative eating nutritiously? Does he or she have contact with others? Are finances being handled appropriately? Are there obvious safety problems?





Answers to these questions will give you an indication of the older person's well-being. If you don't feel that you have adequate time to evaluate the situation or if your aging relative is experiencing confusion, you may want to talk with other family members, neighbors, friends or clergy to secure their opinion of the situation.

One way you and your relative can establish what his or her needs are and develop a plan of support to meet them is by completing the *Care Management Worksheet* on the following pages.

Talk about each concern listed, taking into account your relative's need for independence. In Column A, you'll find comments frequently made by caregivers. If you agree with a statement, place a "1" in the space provided to the left. These are your primary concerns. For each statement you've marked, Column B suggests assistance needed, Column C lists reading materials on the subject, and Column D represents a list of community resources found in most areas.

Following the chart is a bibliography of suggested reading materials and a list of AARP resources. Suggestions for locating community resources begin on page 10.

To use the worksheet effectively, plan ahead. Examine your relative's current situation; ask yourself what would happen if the existing problems become more severe. Imagine the types of services which may be needed.

Place a "2" in the space to the left of Column A for those concerns that you think will be important in the future. These are your secondary concerns which should be addressed *after* you resolve primary concerns.

Care Management Worksheet

Care Management Worksheet

Agree: 1 or 2*	A My Relative	B Services Needed	C Readings** (See Page 6)	D Resources
	...really needs to get out and do something	Socialization/Volunteering —Programs designed to provide an opportunity to socialize with peers or to offer service without compensation	To Serve, Not to Be Served; What Are You? I am Old. Join An AARP Chapter	Nutrition sites, senior centers, day care, friendly visitors, senior companions, YMCA/YWCA, city recreation department, Retired Senior Volunteer Program, AARP Talent Bank
	...can do light house-cleaning but needs assistance with heavy tasks	Chore Services —Window washing, mowing lawn, roof repair, minor housing repair		Local aging social services, area churches or synagogues, fraternal orders, youth groups, neighborhood clubs
	...has some legal matters that need attention	Legal —Assistance with matters pertaining to law	Essential Guide to Wills, Estates, Trusts and Death Taxes	Legal counsels for the elderly, local bar association, Legal Aid, adult protective services, banks
	...is grieving over the death of a loved one	Bereavement Support —Dealing with the normal grieving process	On Being Alone: Survival Handbook for Widows	AARP Widowed Persons Service, THEOS, National Association of Military Widows
	...cannot drive or use public transportation and taxicabs are too expensive	Transportation —Special transportation for older persons		Private transportation, handicapped transportation, Red Cross, churches or synagogues, city elderly transportation service
	...is unable to remain in his/her present housing	Housing —Special housing options are available to the elderly	Housing Options for Older Americans; Your Home, Your Choice; Planning Your Retirement Housing; The Right Place at the Right Time	Retirement community, public housing, foster home, intermediate care facility, nursing home, skilled nursing facility, house sharing, group homes, American Association of Homes for the Aged
	...needs help with food preparation and/or housekeeping and/or laundry	Homemaker Services —Non-medical service to help an older person remain in the home	A Handbook About Care in the Home; Directory of Homemaker-Health Aide Services	Social service agencies, private homemakers, Red Cross, Visiting Nurses Association
	...needs assistance with personal care (bathing, dressing, grooming, toileting)	Home Health or Personal Care Aide —Personal and basic health care provided by a specialist	Healthy Questions; Home Care	Private home health companies, Visiting Nurses Association, Red Cross, private nurses, public health nurses
	...doesn't eat right	Nutrition —Nutritious meals provided at home or group setting	The Cookbook That Tells You How; Handbook of Nutrition, Health and Aging; Eating for Your Good Health	Home-delivered meals, Meals on Wheels, weekend meals programs, nutrition sites
	...cannot be left alone during the day	Friendly Visitors or Intermediate Care Facility —Volunteers who visit with the elderly or a facility which provides constant supervision	Adult Day Care Annotated Bibliography	Adult day care, live-in attendant, social service agencies, foster homes
	...needs special services for physical limitations and impairments	Handicapped Services	Developing Potentials for Handicaps; An Easier Way: Handbook for the Elderly and Handicapped; The Gadget Book	Disease-specific organizations, local office of physical disabilities

*Indicate whether this is a primary or secondary concern by marking 1 or 2

**AARP Sources in bold

Care Management Worksheet

Agree: 1 or 2*	A My Relative	B Services Needed	C Readings** (See Page 6)	D Resources
	...has health care costs which are unbelievable	Healthcare Cost Containment —Reducing cost of quality health care	Information on Medicare and Health Insurance; The Prudent Patient	Medicare-Social Security Office, Medicaid-Department of Human Services, local insurance company
	...is depressed/suspicious/angry all the time, just sits	Mental Health —Evaluation of psychological stability (also see Complete Geriatric Evaluation below)	Creative Mental Health Services for the Elderly; Aging and Mental Health	City Mental Health Department, geriatric social workers, crisis intervention unit, psychiatric hospitals, Alzheimer's Disease and Related Disorders Association
	...is acting strange; could he/she be senile?	Complete Geriatric Evaluation —Medical, psychological and social testing of older person	The Myth of Senility: The Truth About the Brain and Aging; The 36-Hour Day	Have <i>doctor</i> run evaluation of nutritional habits, health, medications and rule out possible illness. Have <i>mental health worker</i> rule out depression. Have <i>neurologist</i> run diagnostic tests. Dementia Resource Center, Alzheimer's Disease and Related Disorders Association
	...really needs 24-hour supervision even though he/she fights it	Private Nurse Or Nursing Home —Homes for the elderly offering 24-hour medical supervision	Family Involvement in the Nursing Home Experience; How to Select a Nursing Home; The Right Place at the Right Time	Private nursing organizations, local ombudsman, homes for the aged, local office on aging, hospital social services, American Association of Homes for the Aging
	...has a terminal illness and wants to return home instead of dying in the hospital	Hospice —Medical and social services designed for terminally ill patients	It's Your Choice: The Practical Guide to Planning a Funeral; A Consumer Guide to Hospice Care	Visiting Nurses Association, Cancer Society, Hospice Association, local hospital social services department, local church or synagogue
	I Sometimes Feel			
	...overwhelmed; I have so many unanswered questions about aging and services for the elderly	Information And Referral —Method of providing knowledge of particular services and recommendations of places providing those services	Caregiving, Helping an Aging Loved One; Understanding Aging Parents; Caring for your Aging Parents: A Practical Guide to Challenges and Choices	Local office on aging, area agency on aging, case manager for elderly, city information and referral
	...I honestly need to share my feelings with someone who would understand	Counseling/Support —One-on-one consultation or meetings with other caregivers who share problems and coping skills	Support Groups for Caregivers of the Aged: A Training Manual for Facilitators; Self-Help Groups for Coping with Crises	Support group for caregivers of the elderly, pastoral counseling, city family services, most social service agencies offering counseling
	...other family members are not helping enough	Family Meeting —Meeting of relatives to discuss responsibilities for elderly care	Aging is a Family Affair; Family Caregiving and Dependent Elderly	Family services agencies, private therapist, case managers, social workers, family therapist
	...my caregiving responsibilities are negatively affecting my work, personal life and health	Physical Exam, Stress Management and Complete Medical Evaluation —Technique designed to alleviate stress and/or increase coping skills	The Relaxation Response; Are You Tense?	Employee assistant personnel or employee counselor, office medical doctor or nurse, private therapist, stress clinics, caregivers in the work place

* Indicate whether this is a primary or secondary concern by marking 1 or 2

** AARP Sources in bold

Care Management Worksheet Bibliography



Socialization/Volunteering

State Communities Aid Association. *What Are You? I Am Old*. New York, NY.

Homemaker Services

National Homecaring Council. (1982). *Directory of Homemaker/Home Health-Aide Services in the United States, Puerto Rico and Virgin Islands*. New York, NY.

Home Health or Personal Care Aide

National Association for Home Care. *Home Care*. Washington, DC.

Nutrition

Watkin, Donald M. (1983). *Handbook of Nutrition, Health and Aging*. Park Ridge, NJ: Noyes Publications.

Zaccarelli, Herman. (1972). *The Cookbook That Tells You How: The Retirement Food and Nutrition Manual*. Boston, MA: Cahners Publishing Company.

Adult Daycare

National Council on the Aging. (1982). *Adult Day Care Annotated Bibliography*. Washington, DC.

Handicapped Services

Russell, Martha and Bantarri, Marlene, Eds. (1978). *Developing Potentials for Handicaps*. Minneapolis, MN: The Minnesota Home Economics Association.

Sargent, Jean. (1981). *An Easier Way: Handbook for the Elderly and Handicapped*. Ames, IA: Iowa State University Press.

Mental Health

Butler, Robert and Lewis, Myrna. (1983). *Aging and Mental Health*. St. Louis, MO: The C.V. Mosby Company.

Glasscote, R. and Gudeman, Jr. (1977). *Creative Mental Health Services for the Elderly*. Washington, DC: The Joint Information Service.

Alzheimer's Disease

Mace, Nancy. (1981). *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementia Illnesses and Memory Loss in Later Life*. Baltimore, MD: Johns Hopkins University Press.

Nursing Homes

McMeekin, Betty. *Family Involvement in the Nursing Home Experience*. Denton, TX: North Texas State University Press.

U.S. Dept. of Health and Human Services. (1980). *How to Select a Nursing Home*. Baltimore, MD: Health Care Financing Administration.

Hospice Care

Coleman, Barbara. (1985). *A Consumer Guide to Hospice Care*. Washington, DC: National Consumers League.

Caregiving

Kenny, James and Spicer, S. (1984). *Caring For Your Aging Parents: A Practical Guide to the Challenges, the Choices*. Cincinnati, OH: St. Anthony Messenger Press.

Lester, Andrew and Judith. (1980). *Understanding Aging Parents*. Philadelphia, PA: The Westminster Press.

Support Groups

Liebermann, Morton. (1979). *Self-Help Groups for Coping with Crisis: Origins, Members, Processes and Impact*. San Francisco, CA: Jassey-Bass.

Rzetelney, Harriet and Mellor, Joanna. (1981). *Support Groups for Caregivers of the Aged: A Training Manual for Facilitators*. New York, NY: Community Services Society.

Family

Begmagn, V. and Hirn, K. (1979). *Aging is a Family Affair*. New York, NY: Thomas Y. Crowell.

Springer, Dianne and Brubaker, Timothy. (1984). *Family Caregiving and Dependent Elderly*. Beverly Hills, CA: Sage Publications, Inc.

Stress Management

Benhamin, Ben. (1981). *Are You Tense?* New York, NY: Pantheon Books.

Klipper, Miriam. (1975). *The Relaxation Response*. New York, NY: Avon Books.

Free AARP Resources

Title	Order Number
To Serve, Not To Be Served	D12028
Join an AARP Chapter	C383
On Being Alone	D150
Housing Options for Older Americans	D12063
Your Home, Your Choice	D12143
The Right Place at the Right Time	D12381
A Handbook About Care in the Home	D955
Healthy Questions	D12094
Eating for Your Good Health	D12164
Information on Medicare and Health Insurance	C38
The Prudent Patient	D12035

To order free AARP resources, send a request listing the title and order number to AARP Fulfillment Section at:

- 1909 K Street, N.W., Washington, DC 20049—for multiple copies.
- Box 2400, Long Beach, CA 90801—for single copies.



Identifying the Informal Support System

AARP Books Cited in Care Management Worksheet

To order any of these books, write: AARP Books, Scott, Foresman and Company, 1865 Miner Street, Des Plaines, IL 60016. Add \$1.75 per total order (not per book) for shipping and handling.

Caregiving. \$13.95 (AARP members \$9.95)

Essential Guide to Wills, Estates, Trusts and Death Taxes. \$12.95 (AARP members \$9.45)

It's Your Choice: A Practical Guide to Planning a Funeral. \$4.95 (AARP members \$3.00)

Planning Your Retirement Housing. \$8.95 (AARP members \$6.50)

Survival Handbook for Widows. \$5.95 (AARP members \$4.35)

The Myth of Senility. \$14.95 (AARP members \$10.85)

The Gadget Book. \$10.95 (AARP members \$7.95)

You and your relative should try to reach a consensus about what supports are necessary. This may not be easy since your perceptions may differ greatly. It is important that your relative remain as independent as possible as long as physical and mental well-being are assured. Even if you may not come to a perfect agreement, try to keep the lines of dialogue open.

Next, examine the informal network already in existence. Most people have friends, fellow club members, relatives or others who already provide some support.

- Sit down with the older person and discuss social contacts. Who are your long-time family friends? Is your relative a member of a social club or recreational group? Are members of religious groups available to provide help? Who are the people your relative has assisted in the past?
- Make a list of those people who are helping your relative now. With your relative, talk with these people to find out exactly what assistance they're providing and list under their names. Don't forget to verify their addresses and phone numbers in case you need to reach them later.
- Explain your situation. Let them know of your concern and how difficult it is for you since you live out of town. Ask these people to contact you if your relative's situation changes. Remember to leave them your phone number and let them know they can call you collect.
- Show your appreciation for the assistance they are currently offering. Highlight its importance. For example, "Mom has told me how much your evening calls mean to her. She really looks forward to them, and I feel more secure knowing that someone is checking up on her well-being."

After you've identified the informal support network, you may wish to expand that network. This can be accomplished in two ways—asking those already involved to take on additional tasks or identifying others who are willing to become involved.

You may be feeling...“How can I ask a complete stranger to provide assistance for my relative?” Keep in mind, however, that persons included on your support network list are concerned about your relative and may be happy to offer other assistance as long as it does not appear overwhelming. Similarly, there are other people whom you have not yet identified who would help if they were aware of the need. A few suggestions for expanding your support network follow:

- Ask for help. Review your *Care Management Worksheet* and support network list. Ask those already providing assistance to increase their support, if possible. For example, “Dad mentioned that you stop by periodically to visit and perhaps pick up something from the store. Dad is really having a difficult time grocery shopping. Would you be willing to stop by once a week to see if he needs something from the store?” Be direct when asking for assistance from new sources. For example, “I heard the Women’s Group provides hot meals to seniors in the community. Please add my aunt’s name to your list.”
- Make the task sound as simple as possible without being dishonest. “Mom really could use your help around the house. You know how neat she is, so you would only need to help with light dusting and the laundry every week or two.”
- Again, show your appreciation. After you return home, send thank-you cards or short letters to persons on your support network list. Reaffirm the importance of their assistance and remind them to contact you if they notice any changes. Remember to continue to show your appreciation from time to time.

In asking for additional support, don’t have several people providing the same assistance. If a person feels unneeded, he or she may discontinue helping. In constructing a support network, the goal is to create a complementary system of assistance whereby as many needs as possible are met. Those needs which cannot be fulfilled by the informal system should be referred to the formal service network.

Expanding the Existing Support Network



Locating and Using Formal Services



Locating formal services is often frustrating. Most persons aren't aware of aging services until a crisis develops. Advance planning, however, will decrease some of the stress involved in locating community resources. Refer to your *Care Management Worksheet*. While gathering information about resources to address primary concerns, be aware of secondary ones. Securing information on secondary concerns *now* may prove extremely beneficial for handling future needs.

Don't get discouraged if the community where your relative lives does not provide all the resources listed on the worksheet. Communities vary in the types of services they offer for older persons. Also, the name used for a particular service may vary. Although these factors can cause confusion and aggravation, there are several effective methods for locating available services.

Talk with knowledgeable people

Social workers, clergy, nurses, physicians and employee counselors may be able to refer you to appropriate services. Neighbors and friends who have used similar services can provide direction.

The government section of your local telephone directory is filled with information. Some examples of headings include the city or county aging department, Social Security Administration, home care services, human services, mayor's or governor's office on aging. There may be personnel in these offices to offer information about other services. Other agencies which offer excellent information and referral services include the United Way, Family Services of America and religious social service organizations, such as Jewish Family Services, Catholic Charities and Protestant Welfare Agencies.

Contact your State Unit on Aging

State Units on Aging are required by law to offer information and referral services (called I&R) at no cost. The states are divided into smaller areas called Area Agencies on Aging (AAA). There are 662 AAA's. The State Units on Aging can refer you to the local AAA that covers the area where your relative lives. Your local AAA will then provide you with information on local community resources. Following is a list of State Units on Aging.

State Units on Aging

Alabama

Commission on Aging
State Capitol
Montgomery, AL 36130
205/261-5743

Alaska

State Agency on Aging
Older Alaskans Commission
Pouch C, Mail Stop 0209
Juneau, AK 99811
907/465-3250

Arizona

Aging and Adult Administration
P.O. Box 6123
1400 West Washington Street
Phoenix, AZ 85005
602/255-4448

Arkansas

Arkansas State Office on Aging
Donaghey Building—Suite 1428
7th and Main Streets
Little Rock, AR 72201
501/682-2441

California

Department on Aging
Health and Welfare Agency
1600 K Street
Sacramento, CA 95814
916/322-5290

Colorado

Aging and Adult Services Division
Department of Social Services
1575 Sherman St., 10th Floor
Denver, CO 80203
303/866-5913

Connecticut

Department on Aging
175 Main Street
Hartford, CT 06106
203/566-7725

Delaware

Division on Aging
Department of Health &
Social Services
1901 North Dupont Highway
New Castle, DE 19720
302/421-6791

District of Columbia

District of Columbia Office
on Aging
1424 K Street, N.W.
Second Floor
Washington, DC 20005
202/724-5622

Florida

Program Office of Aging
Department of Health and
Rehabilitation Services
1317 Winewood Blvd.
Tallahassee, FL 32301
904/488-8922

Georgia

Office of Aging
Department of Human Resources
878 Peachtree St. N.E., Room 632
Atlanta, GA 30309
404/894-5333

Hawaii

Executive Office on Aging
Office of the Governor
State of Hawaii
335 Merchant St., Rm. 241
Honolulu, HI 96813
808/548-2593

Idaho

Idaho Office on Aging
Statehouse—Room 114
Boise, ID 83720
208/334-3833

Illinois

Department on Aging
421 East Capitol Avenue
Springfield, IL 62706
217/785-2870

Indiana

Department on Aging and
Community Services
251 North Illinois Street
Indianapolis, IN 46207
317/232-7020

Iowa

Commission on Aging
914 Grand Ave.
Jewett Building
Des Moines, IA 50319
515/281-5187

Kansas

Department on Aging
610 West 10th Street
Topeka, KS 66612
913/296-4986

Kentucky

Division for Aging Services
Bureau of Social Services
275 East Main Street
Frankfort, KY 40601
502/564-6930

Louisiana

Office of Elderly Affairs
P.O. Box 80374
Capitol Station
Baton Rouge, LA 70898
504/925-1700

Maine

Bureau of Maine's Elderly
Department of Human Services
State House, Station 11
Augusta, ME 04333
207/289-2561

Maryland

Office on Aging
State Office Building
301 West Preston Street
Baltimore, MD 21201
301/225-1100

Massachusetts

Department of Elder Affairs
38 Chauncy Street
Boston, MA 02111
617/727-7751

Michigan

Office of Services to the Aging
300 East Michigan
P.O. Box 30026
Lansing, MI 48909
517/373-8230

Minnesota

Board on Aging
204 Metro Square Building
7th and Robert Street
St. Paul, MN 55101
612/296-2770

Mississippi

Council on Aging
301 West Pearl St.
Jackson, MS 39201
601/949-2070

Missouri

Office of Aging
Department of Social Services
P.O. Box 1337
2701 West Main Street
Jefferson City, MO 65101
314/751-3082

Montana

Department of Family Services
P.O. Box 8005
Helena, MT 59604
406/449-5900

State Units on Aging

Nebraska

Department on Aging
P.O. Box 95044
301 Centennial Mall South
Lincoln, NE 68509
402/471-2306

Nevada

Division of Aging Services
Department of Human Resources
505 East King Street, Room 600
KinKead Building
Carson City, NV 89710
702/885-4210

New Hampshire

Division of Elderly
and Adult Services
6 Hazen Drive
Concord, NH 03301
603/271-4680

New Jersey

Department of Community Affairs
CN 807
South Broad and Front Streets
Trenton, NJ 08625
609/292-4833

New Mexico

State Agency on Aging
LaVilla Rivera Building
224 East Palace Avenue
Santa Fe, NM 87501
505/827-7640

New York

Office for the Aging
Agency Building 2
Empire State Plaza
Albany, NY 12223
518/474-4425

North Carolina

Division on Aging
Department of Human Resources
1985 Umstead Drive
Raleigh, NC 27603
919/733-3983

North Dakota

State Agency on Aging
Department of Human Services
State Capitol Building
Bismarck, ND 58505
701/224-2577

Ohio

Commission on Aging
50 West Broad Street
Columbus, OH 43266
614/466-5500

Oklahoma

Special Unit on Aging
Department of Human Services
P.O. Box 25352
Oklahoma City, OK 73125
405/521-2281

Oregon

Senior Services Division
Human Resources Department
Room 313
Public Services Building
Salem, OR 97301
503/378-4728

Pennsylvania

Department of Aging
231 State St.
Harrisburg, PA 17101
717/783-1550

Rhode Island

Department of Elderly Affairs
79 Washington Street
Providence, RI 02903
401/277-2858

South Carolina

Commission on Aging
Suite B-500
400 Arbor Lake Drive
Columbia, SC 29223
803/758-0210

South Dakota

Office of Adult Services and Aging
Division of Human Development
Richard F. Dreip Building
700 N. Illinois Street
Pierre, SD 57501
605/773-3656

Tennessee

Commission on Aging
Suite 201
706 Church Street
Nashville, TN 37219
615/741-2056

Texas

Department of Aging
P.O. Box 12786
Capitol Station
Austin, TX 78741
512/444-2727

Utah

Division of Aging Services
120 North-200 West
Box 45500
Salt Lake City, UT 84145
801/538-3910

Vermont

Office on the Aging
103 Main Street
Waterbury, VT 05676
802/241-2400

Virginia

Office on Aging
10th Floor
700 E. Franklin St.
Richmond, VA 23219
804/225-2271

Washington

Bureau of Aging and Adult Services
Department of Social and Health
Services, OB-44A
Olympia, WA 98504
206/753-2502

West Virginia

Commission on Aging
State Capitol
Charleston, WV 25305
304/348-3317

Wisconsin

Department of Health and
Social Services
1 West Wilson Street—Room 686
Madison, WI 53702
608/266-2536

Wyoming

Commission on Aging
Hathaway Building—Room 139
Cheyenne, WY 82002
307/777-7986

Try to locate a Silver Pages Directory

This nationwide directory for persons 60 years of age or older lists businesses offering discounts and/or free services. It also contains services offered through the local area agencies on aging in the older person's area. The directory is free to those who reside in the area the book covers. Along with the Silver Pages Directory is a free Silver Savers' Passport Card which can be used at participating businesses to receive discounts and free services.

To order the Silver Pages for your older relative, call the toll-free number, 1-800-252-6060.

Consider consulting with a Private Geriatric Case Manager

A growing number of professionals are offering private case or care management services designed to help caregivers locate and coordinate social services. Each case management organization operates differently, but typically the organization will evaluate the older person's situation, make recommendations, arrange appropriate services and keep family members informed. Usually the caregiver needs to locate a case manager in the city or town where the relative resides. Some case managers, however, have a network of associates in various cities across the country.

Private case management organizations are frequently listed in the Yellow Pages under Social Services, Social Workers, Aging Services, Senior Citizen Services and Home Health Organizations.

Since the field is relatively new, you should keep in mind that private case management organizations are *not* regulated. Fees vary with initial consultations costing \$50 to \$100. You are advised to investigate the services provided and the fee structure in advance. The following section contains some concerns you may wish to discuss before hiring a case management organization.





Accepting Formal Services

Which services does your agency offer?

- ☐ Assessment (evaluates the older person's social, emotional and physical well-being, highlighting strengths and weaknesses). Make sure you understand how the organization defines assessment.
- ☐ Information and referral (provides caregiver with information about and makes connections with local community resources).
- ☐ Completion of forms for needed services (eg. Medicare and Medicaid).
- ☐ Counseling on aging issues for the elderly and their families.
- ☐ Visiting clients.
- ☐ Arranging and/or providing transportation.
- ☐ Accompanying seniors to appointments.
- ☐ Locating alternative housing.
- ☐ Hiring and supervising home care staff.

Staffing

- How many staff persons does your agency employ?
- What are their credentials?
- How long has each staff person worked with the elderly?
- What hours are staff persons available?
- What geographic area does your staff cover?

Fees

- Do you accept Medicare, Medicaid or private insurance?
- What are your fees for the initial consultation? What does the initial consultation include?
- How are your fees structured after the initial consultation (per hour, per service or per job)?
- Do you have a sliding scale? What are the criteria for a reduced rate?
- What is the average cost for your particular needs?

Sometimes the caregiver and/or the older person will have reservations about using formal services. Caregivers may have doubts about the quality of services or reject the idea of strangers being involved with their relative. These feelings can be resolved by realizing that certain needs are better addressed by trained professionals. If you have doubts about social service agencies, often your relative will also be skeptical and perhaps refuse necessary services.

There may be times when you are in favor of a particular service, but the older person refuses to accept agency assistance. Following are suggestions for helping elderly relatives accept services:

- Explain that services are designed to help them remain independent.
- Explain the service.
- Offer to supplement the cost of care, without making your relative feel like you are offering "charity."
- Make arrangements to have the older person pay for the service.
- Offer the service as a gift.
- Have someone the older person respects suggest the service.
- Accompany the older person to gather information about the service.

The process of weaving through red tape to actually get a service started can cause a great deal of anxiety. Service organizations may have a detailed application process, possibly requiring an interview and documentation of medical and financial data. You need to be prepared. The following suggestions are helpful hints for dealing with the social services bureaucracy:

1. *Have a pen and note pad ready.* Make a separate sheet for each service you try to locate. List the name, telephone number and address of each agency that provides the service. List the name, title, department and telephone number of each person you talk with along with their comments and/or recommendations. Save these notes for future reference.
2. *Secure needed information from each agency.* Question each agency providing a service you are interested in about hours of operation, fee, and the application process. Find out if there is someone in the agency, such as a social worker, who could assist you with the application process and be assigned to your case. If your relative is extremely weak or frail, some agencies will conduct home visits to complete the application process.
3. *If an agency requires an interview, be prepared.* Hopefully, you will plan your visit so that you may accompany your relative to necessary interviews. If you are not available, ask someone from your informal support network to go. The person who attends the interview with your relative should be prepared to do the following:
 - Find out what documents will be needed. Make a list of papers taken to the interview.
 - Confirm the appointment a day in advance.
 - Take notes during the interview. Clarify what is going to happen and what are the older person's and the agency's responsibilities.

Dealing with the Social Service Network



Be Honest with Yourself

- *Never* leave an original document. Allow the agency to make copies. When leaving, review the list of papers brought to the interview and make sure all documents have been returned.
 - Keep all important papers together in a folder so that they can be easily located in the future.
4. *Send a note to the agency expressing your satisfaction or dissatisfaction.* A simple note to an organization can really make a difference. If a worker was particularly helpful, a thank-you note will be greatly appreciated and may cause that person to pay closer attention to your relative's well-being. On the other hand, a person who is rude or impolite needs to be reported. You may want to telephone the worker's supervisor and follow up with a letter of complaint to the supervisor as well as the director of the agency.

Caregiving can be a very stressful experience, but especially from a distance. You may experience emotional strain because of feelings of helplessness or guilt at not being able to do more. Sometimes long-distance caregivers schedule several trips within a short period of time, resulting in possible physical exhaustion, conflicts with job and family responsibilities and a depletion of financial reserves.

As a long-distance caregiver, you must be honest with yourself. Recognize the strain you're under and give yourself credit for doing the best that you can in identifying, coordinating and monitoring sources of support. You personally cannot provide from a distance the care your relative needs.

Arranging informal and formal supports for your older relative may not be an easy task if your past relationship with that person has been less than ideal. Honest, open discussion can help. Explain your concerns to your relative and listen to what he or she has to say.

If necessary, you may want to seek out a professional family counselor to help you develop a plan of action acceptable to all parties.

Some long-distance caregivers think that the situation will be easier to handle if the relative moves closer, possibly into their own homes. If you're considering relocating a relative, consider the following questions carefully:

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- Does your relative want to relocate? Many older persons don't want to share a household with other family members. Talk to your relative and find out what he or she thinks.
 - Does your relative have social contacts in your area? Long-standing community ties are difficult to replace. If your relative is limited in mobility, developing new contacts may be highly unlikely.
 - What type of relationship did the two of you have in the past? Unresolved conflicts need to be addressed *before* your relative moves. Be realistic about your previous relationship. If it's impossible for you and your relative to live together, accept the reality of the situation and make other plans.

Whatever arrangement you make—and whether your caregiving remains long distant or not, you need to keep in mind how important a role you're playing. You're helping your loved one live as normal a life as possible.

And whenever possible, remember to extend a little caregiving to yourself.



NOTES

The Women's Initiative is the major effort of the American Association of Retired Persons to strengthen and enlarge the leadership roles held by women; to address the special health, financial, and social needs of mid-life and older women; to create additional opportunities for women to realize their full potential; and to focus attention on the contributions women are making to society.

Because women are most often the caregivers, and because the majority of employees in institutions and agencies providing long-term care services are women, AARP's long-term care efforts are the responsibility of the Women's Initiative.

To find out how you can get involved, or to request any of our publications, write:

American Association of Retired Persons
1909 K Street, N.W., Washington, DC 20049